Working Toward Implementation of HL7 in NAACCR Information Technology Standards:

Meeting Summary Report

Prepared for
the Centers for Disease Control and Prevention
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October 1998

Table of Contents

Executive Summary

From August 19 to 21, 1998, the Centers for Disease Control and Prevention (CDC) sponsored a meeting to explore the feasibility of a standardized electronic exchange protocol for use in cancer registry systems. Meeting participants included representatives from two key organizations, the North American Association of Central Cancer Registries (NAACCR) and Health Level 7 (HL7), as well as CDC staff whose programs have active involvement in the use of HL7 standards (namely, the National Immunization Program, the National Center for Injury Prevention and Control, and the Public Health Practice Program Office).

The meeting began with a series of presentations to educate participants about the characteristics and data needs of cancer registries and the use of HL7 for data exchange. Through the presentations and ensuing discussion, participants explored the benefits and challenges of moving NAACCR toward the HL7 data exchange standard. They also examined a variety of other options other than HL7 for transmission of cancer registry data.

A number of primary benefits of moving toward HL7 standards were identified: greater flexibility to meet current and future cancer registry data needs, improved data quality, expanded query capabilities, compatibility with the trend toward increasing standardization using HL7 in the health care industry at large, a net gain in resources from improved timeliness and efficiency, a broader user base for data products, consistency with regulatory issues and changes, and an expanded pool of software vendors.

In light of these benefits, meeting participants concluded that the HL7 standard had significant advantages over both the current NAACCR standard and other relevant data exchange standards. They thus recommended a transition toward use of this standard, with the first step being the creation of an HL7 implementation guide that would be customized for NAACCR's specific data sources and uses. The guide should build on the results of two recent projects testing the feasibility of using HL7 for cancer registries and CDC's experience of adopting HL7 for immunization, injury, and laboratory program data exchange.

Participants further recommended adoption of the existing HL7 message structure and suggested a preferred method for coding that specifies both the code and the coding scheme origin. This coding structure, which uses existing coding schemes, is simple, avoids the need for design and balloting of new codes, and allows interpretation of the code within the software itself.

Participants also emphasized the importance of a smooth and gradual transition from the current NAACCR system to HL7 and identified a series of additional implementation steps to ensure this transition. These steps included applying for new Logical Observation Identifier Names and Codes (LOINC), testing the specifications in the implementation guide, designing and executing an HL7 consensus-building process, working with vendors to stimulate interest in developing or adapting software, and disseminating the implementation guide and code updates to relevant audiences both inside and outside the network of cancer registries.

I. Background

A. Introduction

Within the last several years, advances in computer technology and the field of informatics have created unprecedented opportunities for improving the completeness, timeliness, and quality of public health data — data previously collected with paper and pencil and exchanged through cumbersome transfers of large databases. Despite their tremendous potential, these opportunities are accompanied by a new set of challenges. These include ensuring that the technological advances occur within a context of synchronized planning by those who use and exchange information.

Both the opportunities and challenges are compelling to the Centers for Disease Control and Prevention (CDC), the North American Association of Central Cancer Registries (NAACCR), and other public health entities that collect and analyze voluminous amounts of health-related data. In addition to CDC's commitment to keeping its own data systems consistent with current standards, the agency also supports the delineation and dissemination of data standards across disease and disability categories. In this capacity, CDC convened a meeting to explore common ground between data collection and exchange features of cancer registries and emerging data exchange standards, specifically the Health Level 7 (HL7) standard.

B. Meeting Purpose

From August 19 to 21, 1998, CDC hosted a meeting of representatives from two organizations: the North American Association of Central Cancer Registries (NAACCR) and the Health Level 7 (HL7) organization. Summaries of relevant information on NAACCR and HL7 are provided below. The purpose of the meeting was to explore the development and understanding of a standardized electronic data exchange protocol for use in cancer registry systems. In addition to the NAACCR and HL7 representatives, meeting participants included other CDC staff whose programs have active involvement in the use of HL7 standards: the National Immunization Program (NIP), the National Center for Injury Prevention and Control (NCIPC), and the Public Health Practice and Program Office (PHPPO). (A complete list of participants and an agenda are provided in Appendices A and B, respectively.)

The meeting began with brief descriptive presentations on the following topics:

- cancer registries and their data needs
- HL7 message content and structure
- universal identifiers and vocabularies used to populate fields in HL7 messages (specifically, Logical Observation Identifier Names and Codes [LOINC] and the Systemized Nomenclature of Medicine [SNOMED]), and
- an initial assessment of the HL7 standard as an alternative to NAACCR's current

exchange protocol, a flat file protocol (the NAACCR-HL7 Mapping Project).

The presentations helped fulfill one important goal of the meeting; to educate each group about the other's perspective regarding data exchange protocols. In addition, the meeting offered opportunities to discuss specific benefits and challenges of moving NAACCR toward the HL7 data interchange standard, as well as potential consequences of maintaining the *status quo*.

Section II of this report explores the potential approaches for using HL7 for cancer registry data exchange; Section III presents the recommendations and next steps that emerged from the meeting.

C. Characteristics and Data Needs of Cancer Registries

What is a cancer registry?

Cancer registries are patient- and disease-oriented databases of information about cases of cancer. The cases, in turn, are defined as independent primary tumors. Although these cases clearly belong to an individual, the tumors (rather than the individuals) are counted for epidemiologic purposes.

In practice, this means that some individuals — approximately 10 % of those with cancer — have more than one "case" of cancer as defined by registries, because they have more than one tumor. The cases are categorized according to medical definitions and adopted conventions. The use of conventions to define cases also means that data for some cancers may not be collected by all cancer registries (e.g., benign brain tumor, basal and squamous cell carcinoma of the skin, and carcinoma in-situ of the cervix).

As each case is reported to a registry, a data set of demographic, administrative, and pathological information accompanies it, including

- date of diagnosis
- demographics (age, sex, race)
- address at diagnosis
- primary site
- histologic type
- summary stage or extent of disease
- date and type of first course of definitive treatment
- vital status
- date of death

Types of registries

Because cancer patients may be treated at multiple facilities and typically are treated for their cancer over a period of months or years, cancer registries must combine data from multiple sources and follow cases over time. Even a facility-based registry (e.g., one in a hospital), which attempts to include all cases of cancer diagnosed or treated in that facility, strives to follow the patient over time and, if needed, include information from other facilities.

Central registries pool data from multiple facilities, such as consortia of hospitals. Some central cancer registries are population-based, such as those based in health departments, in that they include all cases of cancer diagnosed within a particular population at risk. At the state health department level, central registries consolidate data from a variety of sources to assemble an overall record that may include, for example, the diagnosis, first course of treatment, subsequent treatment, and outcome over time for each case. (In addition to the medical records from hospitals, clinics, laboratories, and other facilities, the sources of data for the consolidated record can include other states' registries, death certificates, and Department of Motor Vehicles and voter registration databases, among others). When records represent conflicting information, these conflicts are resolved at the state central registry level.

Uses of cancer registry data

Cancer registry data have multiple uses, each potentially requiring different data sets or approaches. Examples include

- **epidemiology** — the surveillance that reveals trends in cancer
- **cancer control** — e.g., assessing the effectiveness of interventions, targeting populations
- **patient care studies** — evaluating the effects of different treatment regimens
- **patterns of care studies** — e.g., examining whether patients in health maintenance organizations are getting the same services as patients in fee-for-service arrangements.

In order to yield useful data for these purposes, cancer registries need to collect and exchange the following types of data:

- identifiers — patient, facility, and provider
- demographic data on patients
- tumor-specific information
- tumor-specific treatment information
- patient- and tumor-specific follow-up data
- operational data on timeliness that allows monitoring of how a registry system is functioning.

NAACCR's organizational structure

NAACCR was established in 1987 as the umbrella organization for central cancer registries. It provides a mechanism for achieving consensus about standards for registries and publishes those standards as they evolve. In addition to specific registries, a number of partner organizations are represented in NAACCR as sponsors or participants. These include the American College of Surgeons (ACoS), the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program, CDC, and others.

Current NAACCR data exchange standards

The Uniform Data Standards Committee and the Information and Technology Committee within NAACCR work closely together to review and propose changes in data standards and codes. Currently, codes and standards are modified on a yearly timetable, with changes adopted in January each year to meet publication schedules. An updated volume of new standards for data exchange of records is presented in April, in time for NAACCR's annual conference.

Like their counterparts in other large surveillance systems, the current software and codes have evolved from transfers of paper to transfers of discs and data tapes. This transformation has been accomplished using a single–record format. Within that format, there are three distinct record types of fixed length; individual data elements are grouped into different (again, fixed) sections of the record.

D. Health Level 7 (HL7) Overview

What is HL7?

HL7 is the acronym for both an organization (Health Level 7) and the standard that the organization supports and maintains. The organization's goal is to create flexible, cost-effective approaches and standards that lead to interoperability among different health care systems. HL7 membership constituencies include Users, Vendors, Consultants, and government organizations.

Since its first version was released in 1987, HL7 has become a widely adopted standard for the exchange of clinical data. Version 2.3 of HL7 was approved by the American National Standards Institute (ANSI) as an American National Standard in May 1997; Version 3 is under development and is anticipated within 1–2 years.

Summary of Data Standards

Standard	Used to Send and Receive:
HL7	Clinical data
DICOM	Images
ASTM 1238	Batch lab interfaces
X12	Financial and administrative transactions

Although several other data exchange

standards exist similar to HL7 (see box), their history and focus are not clinical data. In many cases, however, the specifications of these other standards are aligned with HL7 technically, allowing them to be used simultaneously, depending on the content and purpose of the data being exchanged.

What is an HL7 message?

HL7 messages are defined for a specific trigger event that can be specified by the user. For example, a user like NAACCR would want trigger events that emanate from the identification of tumors; other organizations would specify different events. The message's content provides the recipient of the data with consistent, verifiable information about the event in question.

HL7 specifications are defined in terms of different message types, each type reserved for a distinct purpose. Message types can describe information about the following topics:

- **Registration** - patient admissions, discharges, transfers
- **Results/observations** - laboratory tests, diagnoses, clinical observations, operative notes, large amounts of text
- **Orders** - by the pharmacy, laboratory, or nurse
- **Billing/charges**
- **Other** - problems, goals, schedules, protocols, clinical trials

Results/observations messages are of primary importance for cancer registries because they convey information about diagnoses, treatment, and outcome. All HL7 messages, however, use a similar structure. The message typically begins with a header that contains descriptive information about the message contents. The message header, the first "segment" in the message, denotes the type of message and the event it describes. The message header is then followed by other segments such as a Patient Identification (PID) segment that would contain patient demographic information and then a set of observations segment (OBR), which identifies the specific "battery" or grouped types of observation about to appear in the following vertical segments — called the OBX segments. OBX segments are the actual "observations" and typically specify the identification, description, value and code source, unit of measure, and observed value status.

Each message segment is comprised of data fields, which are delimited (or distinguished) by vertical bars. Some of the data fields contain distinct data components or data elements separated by a caret(^) .

Although messages may contain many segments, they must contain at least one OBR segment, which can have numerous OBXs to indicate related observations. For example, the codes for stage, site, and extent of disease could be associated with tumor information.

Structure of an OBX Segment

Segment|Set ID|Value type|Identifier Field|Sub Id|Value|Unit|

OBX|1|NM|2857-1^Prostate Specific Antigen^LN|1|7|ng/ml|

The example at the right (see box) depicts the partial structure of an OBX segment. The first portion (OBX) indicates the segment is an OBX segment. The second field is the data type (in this case, NM stands for "numeric"). The third field (known as OBX3) is the identifier of the observation (in this case, a prostate-specific antigen test), and the fourth field sub-ID (1 in this example) is used to distinguish between multiple OBX segments in the same observation grouping. The value of the test can be found in the fifth field (7), and the unit of measurement for that value in the final field (ng/ml). The vertical bars and carets separate data fields and field components, respectively.

One of the advantages of HL7 is that it relies on the adoption of a standard vocabulary, so that all users are defining and interpreting data similarly. Two approved vocabularies for results messages are LOINC and SNOMED.

- **LOINC** (Logical Observation Identifier Names and Codes) is used consistently in the OBX segment 3 (OBX3) to identify the type of observation or test. LOINC establishes standard identifiers codes for clinical procedures, tests, and observations.

- **SNOMED** (Systematic Nomenclature of Medicine) is used in the OBX segment 5 (OBX5) to provide the actual result — the observation value of the clinical procedure or test.

Example Using LOINC and SNOMED Codes

OBX|1|CE|x1234-5^Radiation Procedure^LN||P5-C0300^
Radiation therapy, NOS^SNM|

Cancer-specific information can potentially be reported in the observation (OBX) segment of an HL7 message structure, using LOINC and SNOMED codes. In the example above, the LOINC code x1234-5 is a hypothetical observation identifier for "radiation procedure." The code P5-C0300 in OBX5 is used to indicate the SNOMED code for radiation therapy. Additional cancer-related examples of HL7 results messages using LOINC and SNOMED codes are provided in Appendix D.

II. Use of HL7 for NAACCR Information Technology Standards

Meeting participants were given a list of potential questions to foster discussion on HL7 use in cancer registration (Appendix C). A summary of that discussion follows.

A. Overarching Issues

The primary decision facing NAACCR about HL7 is whether to adopt this standard as the format for reporting cancer registry information — and if so, how to do so with minimal disruption to registries. This decision is a strategic one, based in large part on consideration of how cancer registry data sources and users will interact in the future. If NAACCR envisions a relatively contained system, the current standard may be adequate. However, the more that interactions with other health care entities are envisioned, the more imperative it becomes to ensure compatibility and interoperability between cancer registries and the health care system at large. In this era of computerization, registry systems also need to position themselves to collect and gather their information through a cost-effective and cost-efficient mechanism. At the same time, registry programs need to maintain high-quality data that can be used in developing and evaluating effective comprehensive cancer prevention and control programs.

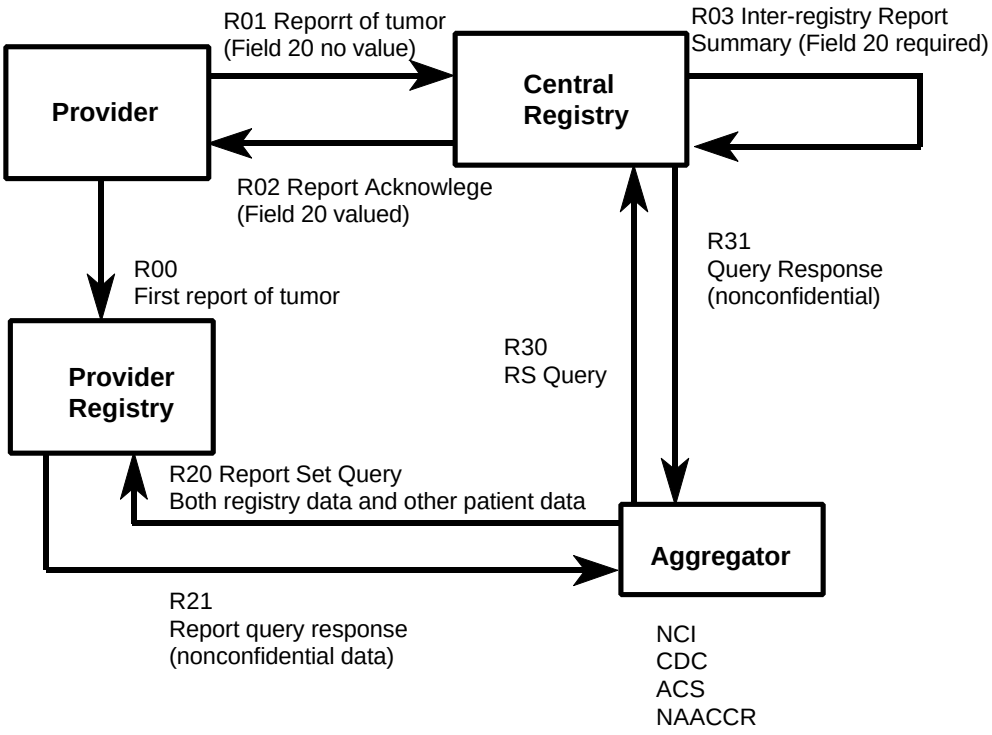
Other factors to consider in making this decision include the need to

- Minimize the duplication of effort in data collection as close to the data source as possible.
- Emphasize interpreted and derived data items rather than actual values.
- Maintain the integrity of existing data.
- Meet the needs of involved organizations (e.g., hospitals and cancer registries).

The enabling technological and strategic advantages that HL7 offers over the existing NAACCR standard are compelling, particularly with regard to data flow and use. For example, built into the HL7 standard are certain trigger (or automatic) events to confirm the presence (or absence) of specific data elements. The system also has the potential for automatic queries between registries, to facilitate collection of data for analysis and decision making.

Figure 1 depicts an example of trigger events initiated by a report of a tumor and the subsequent data flow. The figure describes three types of systematic data flow (I, II, and III), each of which has predefined trigger events that support more automatic transmission and data exchange.

Figure 1: Sample Flow Chart
Trigger Event and Subsequent Data Flow



Type	Name of Trigger	Description
I	R00	Initial report of tumor from provider to hospital registry (NAACCR ID 20= Patient ID)
	R01	Transmission of clinical data necessary to define the initial report from provider (which may not necessarily be the hospital registry) to the central registry
	R02	Acknowledgment from central registry back to provider, which may contain information such as update status or other quality control information
	R03	Interactive transmission of information between central registries
II	R20	Future queries and updates provided from aggregator (at either a regional or national level) to provider registry
	R21	Responses to queries from provider registries, which could allow updates on survival trends compared with national or regional areas
III	R30	Standard query transmissions from aggregate sites to central registries (e.g., on causal updates and data)
	R31	Routine and automated data responses to standard queries from central registry to aggregator

B. Benefits of Moving Toward HL7 Standards

Participants identified numerous benefits of moving toward HL7 standards. These are summarized as follows:

Greater flexibility. The vertical record structure used in HL7 messages would increase the cancer registry's ability to meet currently defined data needs and capture future needs as they evolve. In addition, the coding schemes can evolve separately from the message structure, and successive versions of these schemes can be tracked over time.

Efficient information capture. Increased harmonization of content would reduce the risk of quality problems associated with data entry. HL7 would enable a surveillance program such as cancer registry to insert a trigger event on a stream of data that is already flowing among laboratories, hospital information systems, and other entities. The initiation event detects any predetermined "protocol" that, in effect, says "Send this report to us." The filter automatically recognizes cases and records that are of interest to the cancer registry and forwards them, thus reducing the need to duplicate data entry and improving data quality.

Expanded query capabilities. The capacity of data senders and receivers to exchange standard queries would be greatly enhanced under HL7. For example, with a syntax in place for automated queries, one could request all records within a certain class of tumors with a particular identification or a list of patients sharing a particular attribute. Both specific queries and larger research inquiries could more easily link to counterpart codes and vocabularies used by PDQ, cancer treatment, and protocol literatures. Queries could be more ambitious and yet be performed more automatically than is currently proposed in NAACCR standards. It should be noted that appropriate procedures would have to be in place to ensure the confidentiality of the data being exchanged through these trigger events.

Compatibility with the health care mainstream. Adopting HL7 would allow NAACCR to take advantage of the increasing standardization throughout the health care arena that HL7 represents. If the trend continues and intensifies, as seems likely, some participants argued that maintaining a non-HL7 standard would be akin to maintaining "beta technology in an increasingly VHS environment." Achieving true completeness of data requires interoperability with health care entities outside the immediate world of registries themselves — freestanding clinics, various types of laboratories, smaller hospitals (and those without registries), radiology centers, physicians' offices, managed care organizations, and others.

Net gain in resources from improved timeliness and efficiency, particularly for research. Improved timeliness and efficiency could potentially free up resources for both NAACCR and its organizational and individual constituencies (such as cancer registrars) that are currently devoted to maintaining data sets manually instead of in a more automated fashion. These resources could be used to pursue a broader range of data use for analyses and research than now possible (e.g., analyses of treatment and follow-up

data, pursuit of clinical trials, and initiation of patient interviews immediately following diagnosis).

Broader user base for data products. With more research and lines of inquiry possible, NAACCR's constituency of data users and partners would be expanded. Specifically, relationships with data providers — such as hospitals — could be strengthened if they also use HL7 standards and could more readily use shared information about tumors detected among their client population.

Consistency with regulatory issues and changes. Because HL7 may have a vitally important role in the processing of Health Insurance Portability and Accountability Act transactions involving claims attachments, the use of HL7 will continue to grow. Consistent use of clinical exchange standards like HL7 will continue to facilitate more expedient patient care and data quality. The HL7 organization is also responsive to regulatory requirements; separate monitoring and adjustments would be kept consistent with other data trading partners in the health care industry. For example, proposed changes have already been made to address the structure of the Race field in HL7, which will make the collection of this information more consistent with OMB-15.

Expanded pool of software vendors. As more hospitals and other health care entities move to HL7 and X12 standards (for financial and administrative purposes), the number of software vendors familiar with these standards is anticipated to increase. This would result in a broader pool of vendors available to cancer registries, which are now served by only a handful of software companies interested in the relatively small cancer niche.

C. Challenges

To balance these benefits, participants also noted a number of obstacles and challenges to using HL7. Because NAACCR's current system works, a key challenge would be to convince the NAACCR cancer registry community that the added costs, effort, and potential disruption, although temporary, would be worthwhile. For example, a shift to HL7 would require additional costs for redeployment of new software and would require various procedural and policy changes.

Some constituencies — particularly hospital-based cancer registrars — might feel threatened by the encroachment of increased automation on their roles and functions. In response to this concern, participants noted that similar fears about being supplanted by computers had been voiced by other health care professionals, such as laboratory staff, and yet this scenario did not occur as laboratories became more automated. Indeed, some participants noted that cancer registrars may be freed from the more rote aspects of their jobs to pursue potentially more interesting queries or research projects, or would gradually assume a quality monitoring role, as opposed to a data collection and data entry role.

D. Proposed Approaches

In light of these benefits and challenges, participants explored a variety of options for transmission of cancer registry data. A few of these options involved standards other than HL7:

ASTM 1238 is technically aligned with HL7 and, at one time, the two standards were equally popular. Over the last few years, however, system designers have strongly favored HL7, limiting use of ASTM 1238 to a narrow range of clinical laboratory transactions.

DICOM originated as an imaging standard and only recently has been expanded to handle exchange of clinical data. However, no constituency currently uses DICOM's expanded capacity.

X12 was designed by the insurance industry as a standard for processing claims and other financial or business transactions. As such, it has an administrative orientation but can address clinical data when necessary (e.g., to justify a particular claim). The Health Care Financing Administration (which oversees Medicare and Medicaid) recently proposed the merits of X12 and HL7 for transmission of clinical data, and decided to adopt a structure that uses HL7 within the X12 "envelope."

Participants agreed that none of these standards had significant advantages over the current NAACCR standard and were thus not worth pursuing with any vigor. As for HL7, however, two recent projects help to highlight the feasibility of using HL7 for cancer registries and the options for message structure. The first project maps each NAACCR data element to an HL7 location, and then categorizes the similarities and differences. The second involves preparation of an implementation guide for claims attachment purposes and is in the midst of the HL7 balloting process; approval is expected within 3–6 months, making it an implementation guide template for NAACCR that would have HL7's stamp of approval.

This work, along with the recent experiences of adopting HL7 for immunization, injury and laboratory program data exchange, offers compelling arguments for creating an HL7 implementation guide that would be customized for NAACCR's specific data sources and uses. How to structure the message then becomes the critical issue.

As a result of the mapping project, the crux of the message structure issue for NAACCR was to determine if a new HL7 structure was needed to capture relevant information about a tumor or whether the information could be captured and transmitted using the existing HL7 structure. Each option was presented and discussed at length.

Option A: Creation of a New Segment (or Class in HL7 Version 3)

TUM|Site of Tumor|Stage parameters|...

Option A would combine various aspects of the data needed in the definition of a tumor into one continuous segment. The segment (TUM) would contain various fields (site or stage) that would compose the definition of a tumor. This would have to be balloted and standardized through the HL7 process.

Option B: Use of Existing OBR and OBX segments

PID|...Demographic information, name address, sex, race etc...|...
OBR|||x12222 Tumor Report||...
OBX||CE|x1111^Site of Tumor^LN||C34.9^Lung^ICDO2|...
OBX||CE|x2223^Stage of Tumor^LN||T2^stage^AJCC||...
OBX||CE|x2223^Stage of Tumor^LN||N0^stage^AJCC||...
OBX||CE|x2223^Stage of Tumor^LN||M0^stage^AJCC||...
OBX||CE|x2223^Stage of Tumor^LN||G-F154^T2 stage^SNM||...
OBX||CE|x2223^Stage of Tumor^LN||G-F160^N0 stage^SNM||...
OBX||CE|x2223^Stage of Tumor^LN||G-F170^M0 stage^SNM||...

Option B illustrates that several discrete observations (OBX) would be used to capture the information for a tumor. This information would be reported with the demographic and identification information of the patient contained in the Patient Identification Segment (PID). The LN in the identifier field (OBX-3) is an observation for LOINC codes; SNM and AJCC are the staging codes identified as SNOMED and AJCC, respectively. Note that this is a vertical structure to data transmission as opposed to the horizontal, continuous, unstructured flat file stream of data that is currently processed in NAACCR.

Participants indicated that Option B would provide more flexibility and code granularity and would allow NAACCR room to expand data collection activities. This option would not require balloting changes in the HL7 standard to meet cancer data needs.

An important factor in satisfying NAACCR's data needs with an approach similar to Option B is dealing with the codesets used in the manner for specifying both the code and the coding scheme from which it was derived. The challenge is to use codes from existing HL7 code tables, from LOINC or SNOMED tables, or from some other (yet unnamed) coding scheme. Use of existing schemes avoids the need for the designing and balloting of new codes, a distinct advantage, according to participants. Using the existing LOINC structure necessitates expanding or mapping each existing NAACCR data item to a LOINC identifier code.

A simple example using the registry identifier (ID) variable can be used to clarify the options. For all of these options, the fields would appear in OBX segments and would be preceded by additional HL7 OBX fields.

Option 1: 200^Maine Cancer Incidence Registry^NAACCR0001

In this first option, the first field is the current NAACCR code for the Maine Cancer Registry. The second field is the text description of that code (Maine Cancer Incidence Registry), and the third indicates the coding table used (NAACCR) and the specific code table for registry ID (0001). The text portion (second field) is optional when sending the electronic transmission because it is identified with the code 200 and the table ID NAACCR0001.

Option 2: NAACCR0001.200.^Maine Cancer Incidence Registry^NAACCR
Here the coding scheme and table are incorporated into the first field. The text description is the same as in Option 1 and is again optional (as it is for options 3 and 4 as well).

Option 3: 200^Maine Cancer Incidence Registry^NAACCR
In this option, the first field contains a preassigned code within NAACCR for registry ID (200). All that is needed in field 3 is the name of the coding scheme (NAACCR), because the code values from the registry ID table have been incorporated into field 1. This option is feasible only if all preassigned code values are unique, with each value meaning something distinctly different.

Option 4: 200^Maine Cancer Incidence Registry^NAACCR~1
This option combines the benefits of options 1 and 3, yet adds an identifier for the relevant version of the coding scheme (NAACCR Table 1 for registry ID). It is the simplest of the options and allows interpretation of the code within the software itself. It would also allow for different versions of the table to be transmitted in the exchange (e.g., NAACCR~1.1 could indicate version 1 of Table 1).

The meeting participants agreed that Option 4 would most likely meet NAACCR's needs without incurring some of the cumbersome balloting processes inherent in the other options. Other examples of how segments might be constructed for common cancer registry data items, using Option 4, are provided in Appendix D.

III. Recommendations and Next Steps

The meeting participants agreed to develop a draft implementation plan as a first step in exploring a possible NAACCR transition to HL7. Regardless of the outcome, the transition would not be considered an immediate replacement of NAACCR's existing systems but rather a parallel pipeline of data that would allow a moderately paced transition with comparisons along the way.

Recommended implementation steps are described below.

1. Develop implementation guide.

The implementation guide would assume a similar approach to that currently being undertaken in the HL7 ORU style message structure with OBR/OBX segments and others segments in the ORU message. The OBR/OBX segments could also be used in claims attachments if requested.

The initial effort would involve a straightforward mapping of current NAACCR data elements; major policy shifts or changes would be postponed. Existing vocabulary or values would be used wherever possible or appropriate. It should be noted that SNOMED codes are a very important value field to use in registry coding and their exploration and adoption of these codes should be continued. A significant number of LOINC codes would probably be needed to identify the specific "variables" or existing NAACCR data item numbers. Standard identifiers for the OBR codes would also be needed to group the OBX codes; LOINC codes could be used for this purpose. Application for these codes could occur through the LOINC committee.

The team that volunteered to develop an initial draft included Toshi Abe, Eric Durbin, Barry Gordon, Steve Peace, Lynn Ries, Jennifer Seiffert, Carol White, and Warren Williams. The team would function as an *ad hoc* group, with financial support from CDC for travel to meetings and for similar expenses.

Norman Daoust, Stan Huff, and Wayne Tracy agreed to serve as reviewers and consultants to this team. Dr. Huff offered to identify individuals familiar with HL7 to help with technical issues and to provide an implementation guide template. Copies of comparable implementation guides developed at CDC by NCIPC, NIP, and laboratory program, and through the NAACCR pathology laboratory efforts, would also be useful models.

The group planned to meet during October/November and have a preliminary draft prepared by mid-November/December 1998.

2. Apply for new LOINC codes.

Approval for additional LOINC codes can take anywhere from a few days to several months depending on the complexity of the requested code. In order to prepare a standard implementation guide, LOINC codes would be needed; these codes would be requested from the LOINC committee. A policy should be developed for addressing data items as they arise, so that NAACCR-sponsoring organizations could approach the LOINC committee in an appropriate fashion.

3. Test specifications.

Once the implementation guide is developed, it would have to be tested. Suggestions included finding a software vendor, a hospital with computerized interfaces, or a large organization like Kaiser Permanente willing to test it.

4. Design and execute HL7 consensus-building process.

Building on the benefits highlighted during the meeting, a group of representatives from NAACCR and HL7 would be designated to communicate the implementation guide, test results, potential advantages, costs, policy changes, and other steps required to adopt HL7 standards to NAACCR's board. In addition, particular attention would be paid to marketing the shift to constituencies such as hospital registrars, who may initially feel that their jobs are threatened by this change. There is a need for education on the topic of HL7; as a first step, this topic has been selected for the advanced topics course at the 1999 NAACCR conference.

5. Work with vendors to stimulate interest in developing or adapting software.

A wider array of vendors may be interested in providing programming support to cancer registries once HL7 is adopted as a data exchange standard.

6. Disseminate the implementation guide.

Dissemination of the implementation guide could be accomplished via Internet, CD-ROM, and/or print versions or all these media. Dissemination plans should include processes to assure prompt notification and inclusion of code updates outside the network of cancer registries.

Appendix A:
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Appendix B:
Agenda

Wednesday August 19, 1998 12:30

12:30-1:00 I. Opening Remarks
Warren Williams
Dr. Daniel Miller

1:00- 3:45 II. Mini-presentations of Topics Related to HL7 Use in Cancer Registries

A. Overview of Cancer Registration	Jennifer Seiffert
B. Overview of HL7	Dr. Stan Huff
C. Current NAACCR Data and Exchange Standards	Toshi Abe and Steve Peace
D. Roles of HL7 in NAACCR Document	Dr. Barry Gordon
E. Use of LOINC Codes in HL7 messages	Dr. Clem McDonald
F. Use of SNOMED Codes in HL7 messages	Dr. Steve Steindel
G. NAACCR-HL7 Mapping Project	Warren Williams and Norman Daoust

3:45 - 5:30 III. Group Discussion on Questions and Strategies

Thursday August 20, 1998

8:30-12:00 Continued Discussion of Questions and Strategies

12:00-1:00 Lunch

1:00-5:30 Continued Discussion of Questions and Strategies

Friday August 21, 1998

8:30 -12:00 Definition of Next Seps
Wrap-up

Appendix C:
Questions to Foster Discussion at Meeting

1. What are the benefits of incorporating the HL7 data interchange standard into strategic planning for NAACCR IT (Information Technology) standards? Conversely, what are the consequences if HL7 is not incorporated into NAACCR IT standards? Are there other standards that support the type of data needed in cancer registration?

2. Can the exchange of cancer data be accomplished using existing HL7 messages and codes sets? Does the exchange of cancer data need a new HL7 structure or message that relates to cancer information?

3. What are the criteria used for adopting code sets within the HL7 standard? How can these code sets be used and influenced to better meet the needs of cancer registries? How can HL7 observation reporting be used to meet the needs of registries?

4. Version 3 of the HL7 standard will adopt a new approach to message development. How will the differences between version 2.3.x and version 3 impact NAACCR's planning and use of IT standards for cancer registration?

5. How is harmonization achieved between versions of HL7 standards? How are changes in HL7 versions parallel to changes in NAACCR versions?

6. How will the wider implementation of HL7 within hospital information systems impact the hospital cancer registry and the ability to capture the information that has been traditionally included in a hospital cancer registry?

Appendix D:
Sample NAACCR Data Items

Example of a NAACCR data item using
HL7 Result Message
Data Item number 2112 *Date case report loaded*

OBX|1|DT|x12331^Date report loaded^LN|1|19980819||<CR>

Example of a NAACCR data item using
HL7 Result Message
Data Item number 310 *Occupation text*

OBX|1|TX|11340-7^History of Occupation ^LN|1|Tumor Registrar|<CR>

Example of a NAACCR data item using
HL7 Result Message
Data Item number 270 *Occupation coded value*

OBX|1|CE|11341-5^History of Occupation ^LN|1|226^Pilot^COI|<CR>

Example of a NAACCR text field using
HL7 Result Message
Data Item number 2520 *DX text diagnosis*

OBX|1|ST|8696-7^PHYSICAL FINDINGS Breast^LN||Rt breast: moderately inflamed, erythematous peau d'orange reaction. No palpable nodules. Nipple minimally retracted. 2cm. fullness in mid-rt supraclavicular area & fixed carcinoma
|||||||||19911207|<CR>

Example of a NAACCR field using
HL7 Result Message with LOINC and SNOMED
Data Item number 700 *Chemotherapy at this facility*

OBX|1|CE|11486-8^Chemotherapy Record^LN|P2-67010^Chemotherapy, NOS^SNM|<CR>

Appendix E:
Useful References

Forrey AW, McDonald CJ, DeMoor G, et al. Logical observation identifier names and codes (LOINC) database: a public use set of codes and names for electronic reporting of clinical laboratory test results. Clinical Chemistry 1996; 42(1): 81-90.

McDonald C, Overhage MJ, Dexter P, et al. A framework for capturing clinical data sets from computerized sources. Annals of Internal Medicine 1997; 127(8): 675-682.

National Center for Injury Prevention and Control. Data elements for emergency department systems, release 1.0 Atlanta, GA: Centers for Disease Control and Prevention, 1997.

National Immunization Program. Immunization Data Transaction Using the Health Level Seven (Version 2.3) Standard Protocol, release 1.0.2, Atlanta, GA: Centers for Disease Control and Prevention, 1997.

Web sites:

Health Level Seven (HL7)
http://www.HL7.org

Data Elements for Emergency Room Departments Systems
http://www.cdc.gov/ncipc/pub-res/deedspage.htm

Immunization Data Transaction Using the Health Level Seven (Version 2.3) Standard Protocol
http://www.cdc.gov/nip/registry/download/hl723.pdf